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Citation

Viswanath, K., R. H. Nagler, C. A. Bigman-Galimore, M. P. McCauley, M. Jung, and S. Ramanadhan. 2012. "The Communications Revolution and Health Inequalities in the 21st Century: Implications for Cancer Control." *Cancer Epidemiology Biomarkers & Prevention* 21 (10) (October 1): 1701–1708. doi:10.1158/1055-9965.epi-12-0852.

Published version

<https://doi.org/10.1158/1055-9965.EPI-12-0852>

Link

<http://nrs.harvard.edu/urn-3:HUL.InstRepos:36640989>

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Published in final edited form as:

Cancer Epidemiol Biomarkers Prev. 2012 October ; 21(10): 1701–1708. doi:
10.1158/1055-9965.EPI-12-0852.

The Communications Revolution and Health Inequalities in the 21st Century: Implications for Cancer Control

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Abstract

The radical and transformative developments in information and communication technologies (ICTs) offer unprecedented opportunities to promote cancer control and enhance population and individual health. However, the current context in which these technologies are being deployed—where cancer incidence and mortality *and* communication are characterized by inequalities among different racial/ethnic and socioeconomic status groups—raises important questions for cancer communication research, policy, and practice. Drawing on illustrative data, this essay characterizes the communications revolution and elucidates on its implications for cancer control, with a particular focus on communication inequalities and cancer disparities.

Keywords

Communications Revolution; Cancer control; Cancer Disparities; Communication Inequalities

The radical and transformative developments in information and communication technologies (ICTs) offer unprecedented opportunities to enhance population and individual health. In cancer control, ICTs could play a significant role across the cancer continuum, from prevention, detection, diagnosis, treatment through survivorship or end-of life care. The current context in which these technologies are being deployed—where cancer incidence and mortality *and* communication are characterized by inequalities among different racial/ethnic and social groups—raises important questions for cancer communication research, policy, and practice. This essay will characterize the communications revolution and elucidates on its implications for cancer control, with a particular focus on communication inequalities and cancer disparities.

The Communications Revolution

We live in an information age characterized by two inter-related phenomena: (a) the generation of an enormous amount of data from different sources, whose integration has led to “data deluge,” and (b) a proliferation in the number of information delivery platforms.

Data deluge and information overload

We are generating an enormous amount of information in both public and private sectors. For example, according to *The Economist* (1), the amount of data generated by humankind

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Authors have no potential conflicts of interest to report.

increased from 150 exabytes (a billion gigabytes) in 2005 to 1,200 exabytes in 2010. To put this in perspective, a conservative estimate is that the Library of Congress held 208 terabytes of information as of 2000 (2); an exabyte is roughly equivalent to one million terabytes. While the accuracy of these estimates is contested, there is widespread agreement that we are generating vast quantities of information.

This data deluge (3) stemming from the technological revolution has its functions and dysfunctions. Developments in ICTs have made possible the integration of data from different domains. Combining data with computational algorithms allows processing at great speed, facilitating pattern recognition and new observations that would have been otherwise difficult. For example, pattern matching showed how buying an orange-colored used car is a safer bet compared to other colors; choosing an odd color signified self-expression which, in turn, increased the odds that the owner cared more than usual for the vehicle (4). In the public health context, integrated digital records have the potential to improve patient-provider communications, reduce medication errors and customize treatments.

Yet despite this promise, data deluge also may have negative consequences. In particular, this flood of information leaves little time for processing and reflection, and, ultimately, may lead to cognitive overload. Consistent with this concern, national surveys show that cancer patients are “frustrated and confused” by publicly available cancer information (5). In short, the same technologies that make possible the generation, manipulation, and presentation of large amounts of information simultaneously might overwhelm individuals.

Proliferation of information delivery platforms

A related phenomenon is the dizzying pace at which consumer-oriented devices are available, leading to an increase in the number of platforms through which information can be delivered and accessed. For example, according to the Pew Internet and American Life Project (6), almost 9 out of 10 American adults have a cell phone, more than half have desktop computers, and 6 out of 10 have laptops (Figure 1). Additionally, nearly half have smartphones, devices that simultaneously allow voice and data exchanges. Many adults own more than one device, underscoring people’s increasing comfort with ICTs as well as ICTs’ penetration in everyday life (7). People not only own multiple devices but use these devices for similar functions. For example, more than a third of laptop/desktop news consumers also get news from smartphones, suggesting that ICTs provide increased flexibility, allowing people to access information at the time or place of their choosing.

Consequences of the Communications Revolution

The communications revolution has at least two major consequences with implications for cancer control. One is a shift in how people access and use information, resulting in a fragmentation of mass audience into more closely aligned smaller groups who share common characteristics and interests. Additionally, there has been a shift in audience media use patterns, with the growth of the online audience far outpacing those for other media. Between 2010 and 2011, the percentage change for the online audience was almost four times that of network TV audience and 17 times that of local TV. In contrast, newspapers and magazines lost audience share (7), as people increasingly use digital devices to access news and other information.

Another consequence of the communications revolution is the democratization of information whose generation and consumption was, at one time, limited by specialty and geography (8). For example, while major media with brand names may continue to attract audiences, social media and blogs are siphoning away audiences. Technical reports, scientific articles, and consensus guidelines are now on a variety of websites and available to

anyone with interest and Internet access. For example, the American Cancer Society (ACS) produces an online set of guidelines aimed at the general public that cover key screening guidelines and core prevention messages (9). Major U.S. cancer centers and professional medical organizations also make health information, guidelines, and recommendations publicly available. The National Institutes of Health (NIH) Cones Development Programs (10) routinely posts Conference Statements on its website.

Such posting may not always be intended for the general public, as some information may require a certain degree of sophistication or technical knowledge, but its sheer availability offers opportunities for access and interpretation by different groups. There is an increasing shift in the generation and control of information by larger scientific, academic, government, and private sectors—from a classic command-and-control approach to more grassroots participatory model. Under this participatory model, interested patients, citizens, and interest groups can generate health information and interpret and re-interpret evidence-based information, challenging the establishment version should they disagree with it. There are thousands of blogs and microblogs that offer points and counterpoints on any given health topic. Facts, in short, are subject to framing that may not always comport with the original intentions with which they were generated.

The plenitude of online information is also changing how patients interact with providers based on advice and input from peers and family members. For example, Pew recently reported on peer-to-peer healthcare, which refers to knowledge gained from peers (including caregivers) who are tackling the same health issue—insights that are seen as an important supplement to clinical advice. Patients actively participate in online information exchange, seeking and offering advice and providing social support. Online patients with a chronic disease are twice as likely as those without a chronic disease to create and consume user-generated health content (11). Sites such as *Patients Like Me* use a number of analytical and visualization tools to facilitate gathering and exchange of information among patients or family members sharing similar health conditions. Studies have shown that users report several benefits from participation, and these experiences are related to time spent on the site. In one survey, members indicated that the site informed their decision to start medication (37%), stop medication (22%), and manage symptoms (59%) (12).

Communication has been found to play a central role in cancer prevention and control, given the complexity of cancer etiology, the demands of decision making that accompany detection and treatment, and the needs of patients post-treatment or during end of life stages (13, 14). Thus the developments in ICTs reviewed here offer an unprecedented opportunity to provide information on cancer prevention, monitor lifestyles and health behaviors, promote participatory decision making during cancer detection, diagnosis, and treatment, and foster quality of life during survivorship or end of life.

Cancer Disparities

Ultimately, though, these developments in ICTs are occurring in the context of the continuing differential burden of cancer among racial/ethnic and social groups. Globally, the burden of cancer is expected to rise sharply over the next few decades. In the U.S., however, there has been steady and consistent stabilization, or even a modest decline, in cancer incidence and mortality between 1998–2008 (15). According to the latest status report jointly published by the National Cancer Institute (NCI), the Centers for Disease Control and Prevention (CDC), and ACS (15), average overall cancer incidence declined by 0.6% for men and by 0.5% for women. Similarly, mortality rates declined on average by 1.7% and 1.3% for men and women, respectively. Improvement in tobacco control programs, early detection of cancer, and development and use of effective treatments have improved cancer

rates. Yet these improvements have benefited racial, ethnic, and socioeconomic status (SES) groups differently. For example, the decrease in incidence was not statistically significant among American Indian/Alaska Native (AI/AN) men and women or Black and Asian Pacific Islanders (API) (15). In general, incidence rates were highest for Black men and women.

Reasons for differential disease burden include differences in exposure to risk factors, such as tobacco use or obesity; in access to health care, including routine preventive services; and in treatment, leading to variation in survival and mortality outcomes (16–18). For example, while tobacco use rates are similar between Blacks and Whites, Blacks are more likely to be diagnosed with and die from tobacco-related illnesses (19). Some have suggested that Blacks' smoking more mentholated cigarettes might make it more difficult for them to quit tobacco use (20). Similarly, obesity has been identified as major contributor to a variety of cancers (21), and rates of obesity vary considerably across racial, ethnic, and SES groups.

The story behind the differential disease burden, however, is more complex, and also presents opportunities for more targeted interventions. While much reporting on disparities has focused on race, ethnicity, or social class as discrete categories, recent arguments have drawn attention to experiences and conditions of people at the intersection of these categories (22). An “intersectionality” approach shows, for example, that even though Blacks and women in general are disproportionately affected by obesity, Black women have the highest obesity rates than any other group. In other words, race and sex combined pose a double burden for Black women when compared to other groups. The intersectionality approach draws attention to the different experiences and exposures associated with one's environment and sources of information. It also highlights the differential benefits accrued from social resources, such as education or health care, among different social groups, which, in turn, contribute to the differential burden of cancer. Importantly, these cancer disparities among different racial, ethnic, and social groups are paralleled by differences in access, use, and processing of cancer information—communication inequalities that are explored below.

The Communications Revolution, Communication Inequalities, and Cancer Control

Despite the development and penetration of ICTs, a consistent body of health communication research has found that not all groups are able to take advantage of these technologies. Evidence shows that the same social determinants that are associated with cancer and other health inequalities—such as race, ethnicity, class, and geography—are also strongly associated with communication inequalities (8). Communication inequalities have been defined as *differences among social groups in the generation, manipulation, and distribution of information at the group level and differences in access to and ability to take advantage of information at the individual level* (23). It is our hypothesis that inequalities in communication mediate the relationship between social determinants and outcomes along the cancer continuum, and thus serve as one explanation for cancer and other health disparities (24).

Communication inequalities have been documented along five broad dimensions: (1) access to and use of communication technologies and media, (2) attention to health information, (3) active seeking of information, (4) information processing, and (5) communication effects on health outcomes. For example, analyses of data from NCI's Health Information National Trends Survey (HINTS) tellingly demonstrate differential access and exposure to cancer information across social groups (8, 25) and differential attention to health information (23). In addition, global inequalities in access to and use of ICTs have been observed. For

example, even though cell phone penetration is steadily increasing in both the developing and developed world, the penetration is higher in developed countries (Figure 2); similar trends have been observed in broadband penetration (Figure 3). Of course, differential access to the Internet has been well documented in a variety of studies (8, 26–29), and interestingly enough, the U.S. digital divide also manifests itself in differential access to fixed or wired broadband subscriptions (24, 29, 30). This has important implications for individuals who are looking to maintain a continuous connection to the Internet and integrate access into their daily activities, including using the Internet for health information (31).

A common argument is that the development of ICTs will lower costs and improve access but this argument is questionable. While technology ownership is a one-time investment, continuing access to services is a recurring expenditure. Smartphones are increasingly replacing “feature” phones, making it easier for people to access health and other information online. Yet maintaining subscription is challenging for many poor people. At least in the U.S., telecommunication and cable providers are imposing higher restrictions and greater costs on data use. For example, Verizon recently announced new pricing policies that allow for data, voice, and text to be accessed on multiple devices on a single subscription. Some have argued that this program is likely to increase prices for low-volume users who rely on text and voice (generally poor people), while some high-volume users may potentially benefit from it. While the program’s impact is unlikely to be immediately known, the approach is reportedly being considered by other service providers (32).

Communication inequalities are not limited to information access. As noted earlier, the communications revolution has been marked by the generation of a large amount of information and a multiplicity of channels to provide this information. It is therefore important to understand how people attend to and process this information—and it is not the amount but the *nature* of the information that warrants particular scrutiny.

Consider, for example, media coverage of cancer prevention recommendations. In general, health recommendations are continually updated, as our understanding of disease risk factors and risks and benefits of screening modalities become more nuanced. Although researchers and clinicians are typically well-equipped to negotiate evolving guidelines, it is crucial to understand whether the public is able to make sense of these seemingly ever-changing recommendations. In fact, research has shown that people perceive ambiguity in cancer prevention recommendations which, in turn, is associated with lower preventability beliefs and fewer screening behaviors (33–35). More recently, researchers have linked media exposure to contradictory health information with certain cognitive and behavioral consequences to (36, 37). For example, Nagler (37) found that greater exposure to conflicting information on the risks and benefits of consuming wine, fish, and coffee consumption was associated with confusion about which foods are best to eat and the belief that nutrition scientists keep changing their minds. There was evidence that these beliefs, in turn, may lead people to doubt nutrition and health recommendations more generally—including those about which there is relatively little contradictory information (e.g., fruit and vegetable consumption, exercise). This growing body of research suggests that people notice conflicting information about nutrition, cancer prevention, and other health topics in the media and that this exposure may have important cognitive and behavioral consequences.

A question from a communication inequality perspective is whether there are differences in people’s exposure and capacity to process the large and seemingly contradictory body of health information. In Nagler’s (37) study, those who were less educated reported greater confusion about nutrition research and recommendations than their less educated counterparts. More research on the differential effects of exposure on population subgroups

is warranted, particularly in light of growing controversy surrounding cancer screening recommendations. In the past two years, several guideline changes have been proposed by the U.S. Preventive Services Task Force (USPSTF). In late 2009 the USPSTF issued new recommendations for mammography, downgrading screening for women ages 40 to 49 to a C rating (recommendation against routinely providing the service) (38). This move was followed by a flurry of media coverage (39–41), counter-recommendations from ACS and the American College of Radiology (42–44), and outrage from some breast cancer survivors and advocates (45, 46). In the wake of this controversy, the task force amended the guidelines, emphasizing the value of informed decision making for women under 50 (47). The same pattern was repeated for prostate-specific antigen (PSA) testing with USPSTF's recommendation followed by media attention and opposition by various interest and advocacy groups (48–53). On the one hand, the heightened salience and media attention should lead to lesser gaps in knowledge between higher and lower socioeconomic status groups (23). But, in light of persistent cancer disparities—coupled with the potential for differential effects of exposure to conflicting health information—it is crucial to assess the extent to which underserved populations have been exposed to this controversy and whether it is associated with confusion, backlash towards recommendations, and, potentially, decreased screening intentions.

Even when information is not contradictory or confusing, people often have trouble understanding statistics, and this has implications for medical decision making (54–56). Nearly 4 in 10 people reported in a survey that it was hard or very hard to understand medical statistics (27). The percentages were higher among those with a history of cancer, older people, non-Whites, those with low income, those with less than a college education, students and the unemployed. People with less education and poorer numeracy skills may be more influenced by the way information is framed, such as whether an outcome is described in terms of survival rates or mortality (57, 58). Some types of visual aids have been shown to help those who have low numeracy (58), and there is increasing interest in the use of narratives to help communicate and influence cancer-related decisions (59). Ultimately, the wide array of information outside the medical setting, as well as increased interactivity and evolving technologies, pose challenges and opportunities. While directly marketing vaccines, genetic tests, and cancer treatments to an often innumerate public offers potential advantages to those who understand this information, we also likely need solutions to mitigate disparities in exposure to and understanding of complex cancer-related information, technologies, and treatments (14, 27).

Communication can play a major role in addressing such complexities. Information is essential to improving informed or shared decision making, and cancer patients report seeking information to aid decision making (60, 61). Information seeking, however, is not uniform across social groups. It is well documented that some patients, including those from lower SES, do not seek additional information outside the medical encounter or face major barriers in seeking (62). Similarly, higher SES patients are more likely to seek second opinions and information on self-management or treatments, whereas poorer patients are more likely to seek information on work or finance (63). It is also widely documented that some patients avoid cancer information and may choose not to follow healthy behaviors (64, 65).

Yet the advances brought about by the communications revolution may serve to level the playing field, too. People are increasingly using social media platforms such as *Patients Like Me* to seek information, participate in larger conversations, and obtain social support. This is consistent with the Pew finding that patients with chronic disease typically seek out a provider for information about their diagnosis, prognosis, and treatment, but turn to friends, family, and other patients for emotional support and practical solutions to everyday

problems (66). An interesting dimension to this development is that social media use is less influenced by SES, race, or ethnicity and, in some cases, minorities are actually more likely to use social media. That is, once the issue of Internet access is resolved, participation is more widespread across social, racial, and ethnic groups (67). Similarly, younger people, Blacks, and Latinos are more likely to have smartphones than other groups, as are those of high SES (11). Among those with smartphones, young adults, racial /ethnic minorities, individuals with a high school degree or less, and those with lower household income are more likely than other groups to report that smartphones are their main point of Internet access (6).

Conclusions

Developments in ICTs offer an unprecedented opportunity to overcome the conventional barriers of place, class, and race. It is conceivable that information on cancer risk can be communicated with a greater degree of specificity and customization to different audiences, which may minimize inequalities. It is also possible that greater customization and targeting could make decision making less onerous for cancer patients and improve the quality of life of survivors or those at the end of life. Additionally, ICTs have the potential to leverage the resources that exist among patients, caregivers, and the general public so that social support and other resources are more easily shared. At the same time, patients and caregivers may be better informed and better able to engage in participatory models of care.

Unfortunately, the deployment of ICTs, a 21st century phenomenon, is taking place in the context of classic 20th Century divides of class, place, and race—and they seem to exacerbate these divides instead of abating them (8). This need not be so. A multi-sector and multi-pronged approach could ensure that ICT developments are taken advantage of with the goal of reducing communication inequalities and cancer disparities. These include changes in telecommunication policies that subsidize access to the Internet and online services for the underserved, paying close attention to the information architecture including software to ensure access to information that is comprehensible, and a coordinated effort by professional medical organizations and cancer centers to provide complementary cancer-related information. Last, many underserved groups rely on local community-based organizations (CBOs) for support and services. Engaging local CBOs as information navigators would go a long way toward mitigating cancer-related communication inequalities. Ultimately, if there is a coordinated cancer communication strategy that takes advantage of the communications revolution, it may very well be possible to accelerate the declines in cancer mortality uniformly among all groups, and to stem the potential for growing cancer incidence and mortality in the developing world.

Acknowledgments

The authors of this commentary acknowledge the support from National Institutes of Health: R01 CA122894, R01CA132651-05 and R25 CA057713

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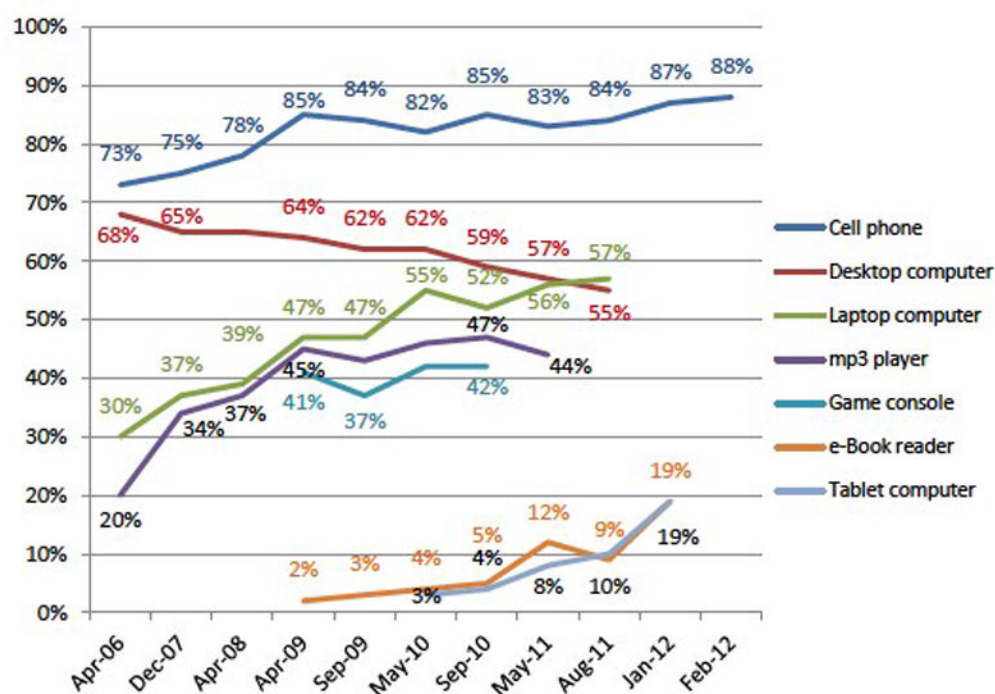
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Adult gadget ownership over time (2006-2012)

% of American adults age 18+ who own each device



Source: Pew Internet surveys, 2006-2012.

Figure 1.

Source: Pew Internet and American Life Project. Adult Gadget Ownership over Time. Available at [http://www.pewinternet.org/Static-Pages/Trend-Data-\(Adults\)/Device-Ownership.aspx](http://www.pewinternet.org/Static-Pages/Trend-Data-(Adults)/Device-Ownership.aspx). Accessed on July 10, 2012.

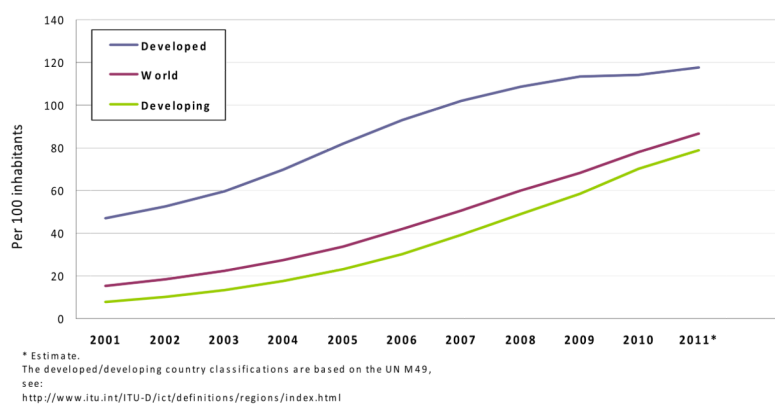
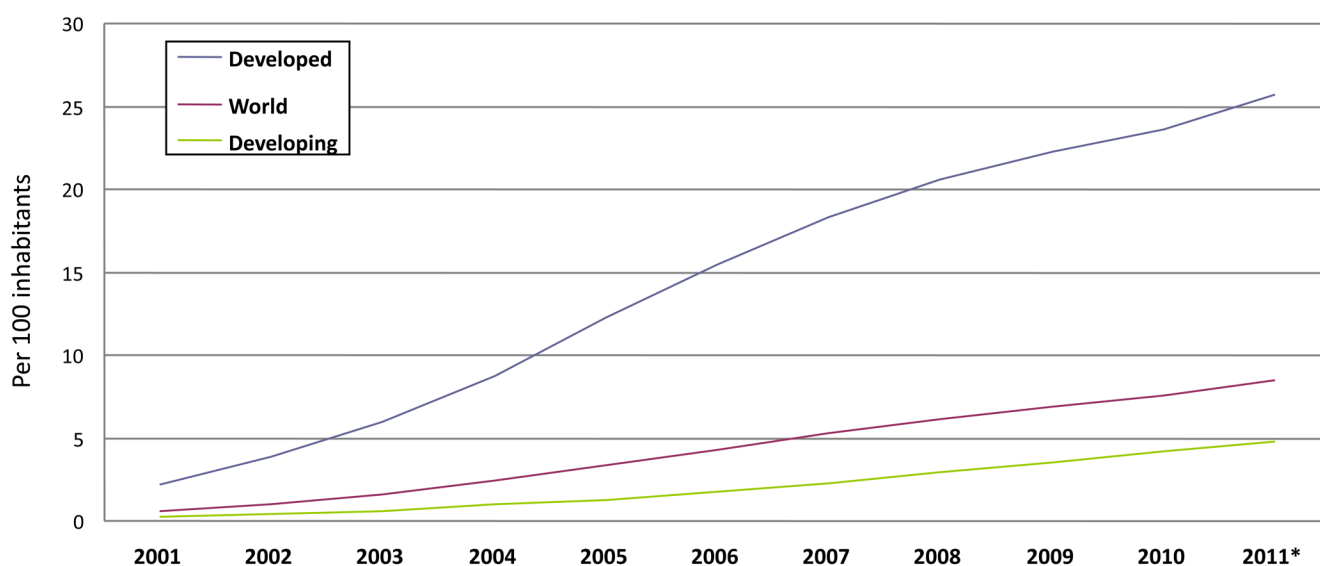


Figure 2. Mobile-cellular subscriptions per 100 inhabitants, 2001–2011*
 International Telecommunication Union [Report on the Internet]. World
 Telecommunication/ICT Indicators Database. www.itu.int/ITU-D/ict/statistics/



* Estimate.

The developed/developing country classifications are based on the UN M49,

see:

<http://www.itu.int/ITU-D/ict/definitions/regions/index.html>

Source: ITU World Telecommunication /ICT Indicators database

Figure 3. Fixed (wired)-broadband subscriptions per 100 inhabitants, 2001–2011*

International Telecommunication Union [Report on the Internet]. World

Telecommunication/ICT Indicators Database. www.itu.int/ITU-D/ict/statistics/, Viswanath et al., 2011